

THE HOW TO HEALTH GUIDE

2016 edition



Disclaimer

Please note that the information on this website is not meant to replace any medical advice provided by your health care team and is strictly a guide to assist you during what can be a challenging journey.

Health Charities Coalition of Canada

41 Empress Avenue, Annex D,
Ottawa, ON K1R 7E9
www.healthcharities.ca



TABLE OF CONTENTS

THE <i>How to</i> HEALTH GUIDE	3
<i>How to</i> UNDERSTAND THE HEALTH CARE SYSTEM	4
<i>How to</i> FIND THE INFORMATION AND SERVICES YOU NEED	5
Health Charities	5
<i>How to</i> REVIEW AND EVALUATE HEALTH INFORMATION ON THE INTERNET	6
<i>How to</i> TALK WITH YOUR DOCTOR OR HEALTH CARE PROVIDER	7
Patient Rights and Responsibilities	7
What to Say	7
What to Ask	8
<i>How to</i> ASK FOR A SECOND OPINION	9
<i>How to</i> MANAGE YOUR CONDITION	9
<i>How</i> MEDICATION COVERAGE WORKS ACROSS CANADA	11
Private Coverage	11
Public Coverage	11
Out-of Pocket (Cash)	12
Pharmaceutical Companies	12
Catastrophic Drug Coverage	12
<i>Advocating</i> FOR YOURSELF	13
<i>How to</i> PARTICIPATE IN A CLINICAL TRIAL	15
Questions to Ask Your Doctor if You are Considering Participating in a Trial	15
<i>How to</i> ADVOCATE FOR AND GET THE SUPPORT YOU NEED	16
<i>Tell</i> YOUR PERSONAL STORY TO HELP CREATE CHANGE	17
Share Your Story	17
<i>Background</i> INFORMATION: THE FEDERAL GOVERNMENT AND HEALTH CARE	18
THE <i>Provincial and Territorial</i> GOVERNMENTS AND HEALTH CARE	19
Provincial and Territorial Ministries of Health	19
Provincial and Territorial Regional Health Authorities and Organizations	20
Provincial and Territorial Call-in Health Lines	20

THE Drug Approval PROCESS IN CANADA	21
Special Access Program	21
Common Drug Review	22
L'Institut national d'excellence en santé et en services sociaux (INESSS).....	22
Clinical TRIAL PHASES	23
Genetic DISCRIMINATION	24
Advocacy TOOLS AND TECHNIQUES	25
Political and Systemic Advocacy	25
Personal Advocacy	26
Step 1 – Develop Your Key Messages.....	26
Step 2 – Advocacy Tools	29
A Description of Some Advocacy Tools.....	29
Step 3 – Your One “Ask”	30
Appendix	31
Recognition of Sponsors	31
Recognition of Contributors	31
2015 Members of How-to-Health Guide Working Group.....	32
2015 Members of HCCC’s Standing Committee on Health Policy and Advocacy.....	32
List of HCCC Members	33
List of HCCC Affiliate Members	35

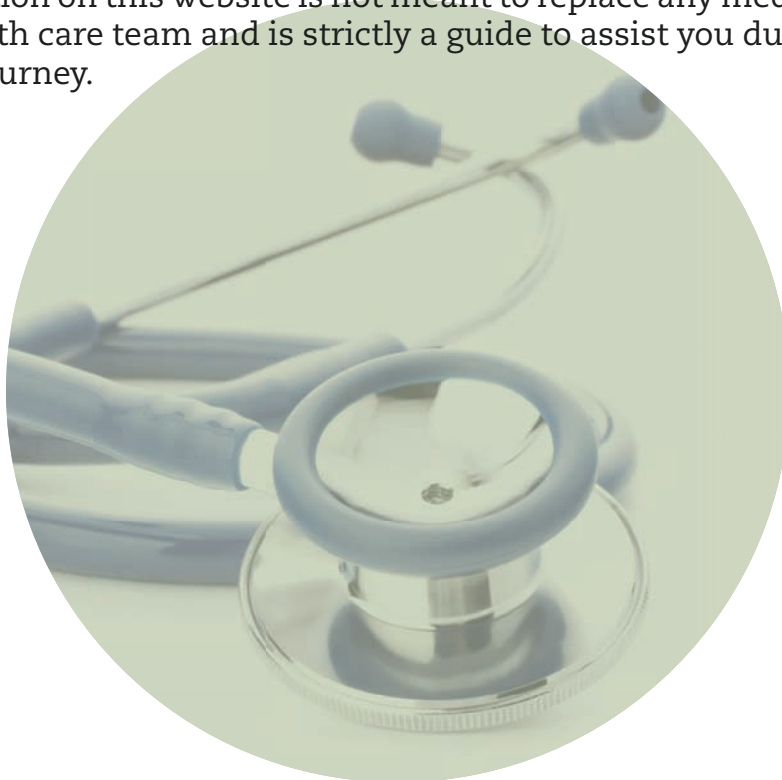
THE HOW TO HEALTH GUIDE

If you or someone you love and care for is trying to find health services, support or information for an illness or disease, there are actions you can take to help get the best possible care.

This is a guide to help you learn how to:

- **Understand** the health care system
- **Find** the information and services you need
- **Review and evaluate** the information you find
- **Talk** with your doctor or health care provider
- **Ask** for a second opinion
- **Manage** your condition
- **Pay** for your medication
- **Participate** in a clinical trial
- **Advocate** and ask for the support you need

Please note that the information on this website is not meant to replace any medical advice provided by your health care team and is strictly a guide to assist you during what can be a challenging journey.



HOW TO UNDERSTAND THE HEALTH CARE SYSTEM

Canada has a publicly funded health care system known as *Medicare*. Medicare provides free, medically necessary services such as hospital care or an appointment with a physician. To understand the health care system, you need to learn how the federal, provincial and territorial governments, and in some cases, health regions, are involved in the delivery of health care.

The **Federal Government's** health care responsibilities include:

- Determining national principles for the health care system. For more details, see our section: Canada Health Act (p.19)
- Providing financial support to the provinces and territories to deliver health care services
- Directing delivery of health care services to:
 - First Nations people living on reserves and Inuit
 - the Canadian Forces and the Royal Canadian Mounted Police
 - eligible veterans
 - inmates in federal penitentiaries
 - refugee claimants

For more information, see our section: Federal Government and Health Care (p.18).

The **Provincial and Territorial Governments** plan for and provide Medicare free of charge to its residents. Medicare covered health services are funded through taxes. Most provinces and territories also provide additional services for certain groups (e.g. low-income residents, those within the last six months of care and seniors) including:

- Drugs prescribed outside hospitals and ambulance costs
- Hearing, vision and dental care not already covered

Most provinces and territories have **health regions** to administer public health care services to Canadians. Health regions are also referred to as regional health authorities, Local Health Integration Networks (LHINs) or health agencies. Many provinces and territories also have telephone health information lines. To see this information, go to our section: Call-In Health Lines (p.20).

In addition, each province and territory has a **workers' compensation agency**, funded by employers, which provides services to workers injured on the job.

As you age you might need additional levels of care. These can be provided at home through home care programs. Those in active care can access it through hospitals or continuing care facilities, and those at end-of-life through residential hospices or a long-term care facility. For more information, see our section: Provincial and Territorial Governments and Health Care (p.19).

HOW TO FIND THE INFORMATION AND SERVICES YOU NEED

One of the first steps is to learn all you can about your disease or condition and the treatments available. Being knowledgeable will help you make informed decisions.

There are many sources of health-related information including:

- Your family doctor and your local hospital
- Patient Groups/Health Charities
- The Internet and the public library
- Other health professionals such as your pharmacist, physiotherapist, psychologist, occupational therapist and social worker
- Community health service centres and public health professionals such as nurses and dieticians
- Alternative medical practitioners such as chiropractors, naturopaths and acupuncturists

For more information, see our section: Provincial and Territorial Governments and Health Care (p.19).

HEALTH CHARITIES

There are a number of health charities in Canada that provide support for patients as well as their caregivers. They do this by providing patient education programs, disease and treatment information, patient support groups, online discussion forums, various rehabilitation programs and patient self-help management programs.

In many cases, health charities work with physicians and other health care professionals who can help answer specific questions you may have. For more information, see our full list of members at the Health Charities Coalition of Canada website (www.healthcharities.ca/membership/our-members.aspx).

HOW TO REVIEW AND EVALUATE HEALTH INFORMATION ON THE INTERNET

The Internet is a convenient source to find health-related information. However, anyone can easily post any information they want, even if it's not true. Ask yourself the following questions to decide if you can trust information you find online. Ask the following questions to help determine if the information is credible, independent and unbiased.

- Who supports the website? Who maintains it? Who pays for it?
- How current is the information? Does the site post the date and when it was last updated?
- If the information on the site is not original, does the site provide references about the source of the information?
- Does the site display the name/logo of the institution or organization responsible for the information?
- Does the site display the author's name, qualifications and credentials if relevant?
- What do other associations think of the site? Does it meet their approval?
- What is the purpose of the site? Is it to give you information or to sell you a product? Is the site a vehicle for advertising?
- Does the site post a disclaimer describing the limitations, purpose, scope and authority of the information?
- Are they asking too much information about you?
- Is the information balanced or more one-sided?
- Does the site post links to other appropriate sites so you can read more?
- Is the site well designed so you can navigate it easily?
- Is there a way to send comments and feedback on the site?

To learn more about how to review and evaluate information on the Internet, visit the Canadian Breast Cancer Foundation website (<https://www.cbcf.org/ontario/AboutBreastCancerMain/ResourcesBC/Pages/Understanding-Web-Health.aspx>).

HOW TO TALK WITH YOUR DOCTOR OR HEALTH CARE PROVIDER

PATIENT RIGHTS AND RESPONSIBILITIES

As a Canadian patient, you have rights. You have the right to treatment, a right not to be refused urgent care, a right to diagnosis, a right to coverage, and even a right to appeal if you think your rights have not been respected.

You also have responsibilities such as providing accurate information to your health care team, asking questions to make sure you understand the information being shared with you and following your treatment plan. It is important for you as an individual, to take an active role in your health care. To make sure you get the answers you need about your disease or condition and treatment, educate yourself and learn how to talk to your doctor and other members of your health care team.

Many people feel anxious when they are first diagnosed and can be nervous when they talk to their family physician or specialist. This section provides information about questions to ask the doctor, tips on how to get all the information you need out of each appointment and how to ask for a second opinion.

WHAT TO SAY

Before you see the doctor, make a list of the following information. Start to make the list well in advance of your doctor's appointment. If you try to remember all of this information the day before, you may forget some important points. Be sure to include information on:

- All of your symptoms – for example, your experience with pain, sleeplessness, cough, headache, trouble breathing, anxiety, depression
- How long you have had each of the symptoms – for example, joint stiffness in the morning over the past 3 months
- How you feel during the course of a 24-hour period – for example, stiffness in the morning when waking, nausea following meals, headache in the afternoon and throughout the evening
- List what you have tried already, what helps and what makes it worse
- List all the medications that you are currently taking including prescription drugs, over-the-counter medications, herbal remedies, supplements

WHAT TO ASK

During your appointment with the doctor or health care professional, do not be afraid to take notes. We often forget what we are told during our appointments with physicians. You may wish to bring a family member or friend along to medical visits to make sure you don't miss important information. As a courtesy, tell your doctor why you are taking notes. Below is a list of questions that you may want to ask during your appointment:

- What do you think is wrong with me? What is my diagnosis?
- Do I need to have test(s)? If so, when will I have the test(s)?
- What is the reason for the test(s)?
- When and how will I get the results from my test(s)?
- What are my treatment options?
- What are the next steps?
- Does the hospital, clinic, medical office, etc., have a social worker or patient advisor that can help me to better understand the next steps?
- Do you have any patient information sheets or brochures that I can read to educate myself?
- Where can I get more information about my condition?
- Is there information to help members of my family understand what I am going through? Is there support for them?
- Is there a health charity or support group I can contact for my particular disease or condition?
- Are there any lifestyle changes that I need to make?
- What more can I do for myself to help improve my condition?
- Is there a self-management program that I should attend?
- Who should I contact/where should I go if I start to feel worse?



HOW TO ASK FOR A SECOND OPINION

Do not be afraid to seek a second opinion about your health. It is your right as a patient since a second opinion may help you learn more about your disease, gain a different perspective on treatment options, and provide reassurance and peace of mind that you are making the right treatment decisions.

Many patients worry about telling their doctor they plan on seeking a second opinion, but they shouldn't. Most doctors are comfortable with the request, particularly in the case of a serious disease diagnosis.

If you have been diagnosed with a serious illness and would like a second opinion but are nervous about offending your specialist, ask your family physician to make the referral to a second specialist.

HOW TO MANAGE YOUR CONDITION

Patients with chronic and even terminal conditions can contribute to their own care through patient self-management programs. Self-management programs help you, as well as your caregiver, to better understand your disease or condition, teach you how to cope with your symptoms and show you how to be more involved in managing your disease and care.

Self-management programs usually include information about:

- Managing physical symptoms to reduce negative impact on daily living (e.g. pain, stiffness, bowel and bladder issues)
- Physical activity
- Nutrition
- Avoiding tobacco use
- Limiting alcohol consumption
- Taking medications properly
- Dealing with stress and/or depression

- Working with your doctor and health care team to make the best treatment and care choices for you
- Evaluating alternative treatments
- Planning ahead with your family and health care team to obtain appropriate assistive technology if necessary to help with activities of daily living
- Talking to your physician and substitute decision maker about developing an advance care plan

The benefits of self-management programs could include fewer trips to the doctor, better control over your disease or condition and possibly improved overall wellness. Current end-of-life care research increasingly suggests that Canadians prefer to die at home or in their home communities (e.g. in long-term care facilities or hospices) instead of in a hospital setting. People near end-of-life should receive the care and support they need wherever they are. Patients can and should move freely and easily between settings of care.

Even if your condition is certain to worsen over time and may be life limiting, managing symptoms and making timely decisions about care and support can prevent unnecessary injuries, infections, fatigue and may increase survival time and quality of life.

At the end of life, many people require the support of family and caregivers. There are a number of caregiver support programs at various levels of government.

Federally you might qualify for the Compassionate Care Benefit through the Employment Insurance Program. The Compassionate Care Benefit is a program wherein you can receive up to a maximum of 26 weeks of income support if you have to be absent from work to provide care or support to a gravely ill family member at risk of dying within 26 weeks.

At the provincial level, home support coverage may be available to individuals as well.

Ask your doctor, health care professional or health charity representative if there is a self-management program or resource available for you.



MEDICATION COVERAGE WORKS ACROSS CANADA

There are three main ways that drugs are funded in Canada: privately, publicly, or out-of pocket (cash). In addition, pharmaceutical companies and provincial plans can provide support in special circumstances.

PRIVATE COVERAGE

Employers can purchase drug plans from insurance companies and offer it to their employees as a job benefit. Roughly 60% of Canadians receive private drug coverage from their employers. These plans are comprehensive and will cover most approved drugs. Employees are usually protected from any costs when they receive a prescription except for a modest dispensing fee at the pharmacy. However, these plans can be quite expensive and may not be affordable for employees at small companies, those being self-employed, or those that are un-employed. In addition, people living with chronic conditions or illnesses, insurance companies will often attach higher premiums, or even decline applications in order to balance the cost of the benefits against the risks being taken.

PUBLIC COVERAGE

Overall, Canadian governments pay for just under half of the total drug costs. Each province creates a list of medications (called a drug formulary) that it will cover for its residents. The formulary is created to address the health needs of that particular province. Since the demographics, health needs and budgets are different in each province, the drug formularies between provinces can also be different. This means that one drug could be covered in B.C. and not in Ontario for example.

Each province manages its own health and drug plans and as a result, the requirements to be eligible for coverage can also vary from province to province. For example, to have coverage on the Ontario provincial formulary you need to be above 65 years old. Where as to have coverage on the B.C. provincial formulary you need to first reach an income based deductible.

For a drug to be included on a provincial drug formulary, it must go through a critical evaluation process. This typically results in more drugs being included on private plans and in a more timely manner.

OUT-OF POCKET (CASH)

If you have neither private nor public coverage for your prescription, you would be required to pay for your own prescription. Even if you are eligible for coverage under one of the public plans, you may still be required to pay some amount in the form of either a:

- co-payment (a flat fee that you pay with each prescription);
- co-insurance (a percentage that you pay with each prescription);
- deductible (a certain amount that you pay with each prescription until you reach a maximum amount, at which time the public plan pays 100%); or
- premium (a payment you make whether or not you receive a prescription).

PHARMACEUTICAL COMPANIES

Some pharmaceutical companies have free services that will help you access the drug you require. Talk to your doctor or medical care team or search online to see if you are eligible. Some pharmaceutical companies provide drugs or medical supplies to patients who are unable to afford them or who do not have public or private insurance, through Compassionate Use Programs. Each product has its own terms for eligibility and these Compassionate Use Programs should not be considered a replacement for public or private insurance coverage.

CATASTROPHIC DRUG COVERAGE

Most provinces and territories provide coverage for residents who spend a portion of their income on prescription medications or for certain high-cost drugs. The aim of catastrophic drug programs is to protect Canadians from the large financial burden of drug costs. These programs are not meant to replace private insurance plans or publicly funded drug plans. Contact your ministry or department of health (p.19) to find out if there is a plan available for you.



ADVOCATING FOR YOURSELF

Managing your health care or a loved one's health can be a daunting task. Persistence, communication, documentation and information are key to advocating for appropriate care. Here are tips to guide you through the most common scenarios:

a) **About Group Benefits**

If you are employed and have access to benefits such as life and disability insurance and drug coverage be sure to find out and understand the details of your employer's group benefit package. Talk to your Human Resources department and learn about what you can expect if you make a claim.

When leaving your employer, your benefits will also terminate. If you are not going to a new employer you will need to consider obtaining individual private insurance. If you live with a condition(s) or illness you may find that the premiums quoted to you are high. Weigh this against the fact that you will not be rejected by the insurer and you will at least have coverage – only you can determine if this is the best choice for you.

b) **If Your Claim is Rejected**

Assuming that you have found insurance, there may be times when you have to make a claim – and times when that claim is rejected. First of all, be sure of your rights under your policy. Check to make sure that you have not made a claim for something for which you are not entitled.

If you think you are entitled, don't let the first, or even the second rejection stop you. Persistence is key. Use the appeals process that your policy has and be sure that your physician is on board and is supplying the necessary supporting documentation to your best advantage. This may be a case of insufficient information that is causing the rejection.

Contact the insurance company's Ombudsman or Complaints Officer. He or she is there to assist consumers with complaints. If you are still not satisfied, request a letter from your insurance company, stating their final position and supporting documentation. You can then use the free, national services of the impartial OmbudService for Life and Health Insurance (OLHI) to help you with your claim. Be sure to keep a file of all your correspondence and medical information so that the ombudsman can conduct a thorough review of your case.

Recruit the assistance of your Human Resources (HR) department if you are a member of your employer's group benefit plan. Staff in that department should be able to help you with your claim and in some circumstances, the employer has enough persuasive power to help overturn the rejection or get certain drugs added to an approved formulary list.

c) I'm insured but my drug is not covered

If it is your employer who has excluded certain drugs from the approved list of medications for reimbursement, at this point, you may decide to disclose your condition to your HR manager. Describe your condition and ask that your employer either update the drug plan to include your drug as part of the plan or make an exception. If not covered, ask your health benefits manager (often the HR manager) why they decided not to cover the drug? Perhaps there is alternative coverage, maybe you need to apply to get access to alternate coverage. Ask if there is an opportunity to apply for interim coverage.

It is in the best fiscal interests of an organization to keep their staff healthy and on the job. It is important that you document all of your communication and exchanges with your plan sponsor and/or insurer.

d) Supplementing Private Insurance

Some individuals may wish to purchase private coverage or supplement existing coverage they already have. You may want to consider working with an insurance agent, especially one who is familiar with and specializes in chronic conditions or illnesses. Insurance premiums remain the same whether you purchase your policy by yourself or through an agent. It is important that insurance applications are completed accurately and a licensed agent can make sure that medical questions are answered completely and in detail.

For more information on prescription drug reimbursement in Canada, go to the Drug Coverage Guide to Reimbursement website (<http://www.drugcoverage.ca/en-ca/>).

If you are interested in learning more about how drugs are reviewed and approved in Canada, see our section on The Drug Approval Process (p.21) (http://www.hc-sc.gc.ca/dhp-mps/prodpharma/activit/fs-fi/reviewfs_examenfd-eng.php).

HOW TO PARTICIPATE IN A CLINICAL TRIAL

Drugs are tested in a number of different ways before they are submitted to Health Canada for approval. One of these ways is through clinical trials. A clinical trial is a research study which uses volunteers to determine whether or not a new treatment, drug or device is effective and safe.

It can take up to five years, or even longer in some instances, to ensure that newly developed treatments are safe for research with human participants. Each clinical trial has a set of rules (protocols) for the research which will outline eligibility criteria for participants (age, gender, medical history, etc...), the number of participants they need, how long the trial will last, treatment details and information about some of the potential side-effects. For more information about the development of clinical trials, see our section: Clinical Trial Phases (p.23).

You may be interested in participating in a clinical trial because it makes a valuable contribution to research and may give you access to new treatment before it becomes widely available. There are some risks such as unknown side-effects and/or there may be additional costs involved in participating in a clinical trial (e.g. more frequent travel to the study site). If you are interested in participating in a clinical trial, you should talk to your doctor and make sure you understand all of the facts (informed consent) before making your decision.

QUESTIONS TO ASK YOUR DOCTOR IF YOU ARE CONSIDERING PARTICIPATING IN A TRIAL

- What is the purpose of the study?
- How does it support progress toward a better treatment and cure?
- Who has reviewed and approved the study?
- What are the risks? What are the benefits?
- How does this treatment compare with other treatments available?
- What kinds of tests and procedures will be required? Where will they take place?
- How long will I receive the treatment?
- Will the study require extra time, effort or expenses on my part?
- What does my family need to know?
- Where can I learn more about the study and the researchers involved?

Health charities are often a valuable source of information about various clinical trials for specific treatments available in Canada or the United States. For more information, see our list of members at the Health Charities Coalition of Canada (<http://www.healthcharities.ca/membership/our-members.aspx>). Other sources of information include the Canada Trials website (<http://www.canadatrials.com/>).

For more information about the types of questions to ask yourself to about participating in a research study, see the Canadian Breast Cancer Foundation's "Making Sense of Research Studies" publication (<https://www.cbcf.org/ontario/AboutBreastCancerMain/ResourcesBC/Pages/Understanding-Research.aspx>).



HOW TO ADVOCATE FOR AND GET THE SUPPORT YOU NEED

If you or someone you love or care for is not receiving appropriate care from the health care system, there are steps you can take to effect change. Speaking out to make a change is referred to as advocacy. Successful advocacy is based on your ability to identify and explain your issue and propose an effective solution.

1. What is your issue? What do you want to see changed? Why does it concern you?
2. Who do you need to talk to? Who has the authority to make the change? (The hospital? The Minister of Health? Your insurance company?)
3. How will you explain your issue? What can you do to deliver your message? (A letter? A meeting? Both?)
4. When asking for a change, keep your request or "ask" to just one. This will help you to focus on the thing that you need the most and not a list of things that you would like to have.

Be sure to contact the health charity/organization associated with your condition to see if they are already advocating for the same issue(s) you are.

TELL YOUR PERSONAL STORY TO HELP CREATE CHANGE

Telling your personal story is a very powerful and effective way to help create change. Whether you are speaking to a politician, government official, other advocates or the media, your personal story helps to bring the issue to life and adds importance to the solution. Your personal story allows you to connect in a meaningful way with key decision makers.

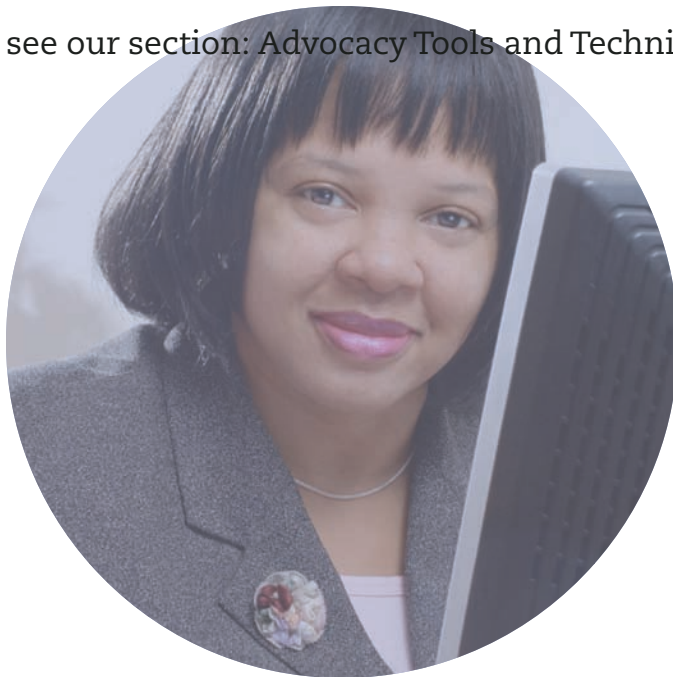
There are things you should keep in mind when you are preparing to tell your story to help get the message across:

- **Be clear:** what is the issue? How has it affected you? What do you want to change?
- **Be brief:** you should take no more than 5 minutes to tell your story
- **Be personal:** share your experiences, feelings and observations about how this has affected your life

SHARE YOUR STORY

In order to show others how patient advocacy works, we kindly ask you to share your story. If you have been successful in creating change to improve the health care system, please share your story with us by sending an e-mail message no longer than 200 words to the Health Charities Coalition of Canada (info@healthcharities.ca). Please include your name and contact information so that we can reach you if needed. We will post your story on our website so that others may benefit from your experience. We will not post any personal information.

For more information on advocacy, see our section: [Advocacy Tools and Techniques](#) (p.29).



BACKGROUND

INFORMATION: THE FEDERAL GOVERNMENT AND HEALTH CARE

In order to receive federal funding for health care, each provincial and territorial government must meet five criteria as stated in the federal government's Canada Health Act (<http://www.parl.gc.ca/content/lop/researchpublications/944-e.htm>).

Description of the **five criteria** for delivering health care:

- **Public Administration:** must be administered and operated on a non-profit basis by a public authority that answers to the provincial or territorial government.
- **Comprehensiveness:** must insure all medically necessary services provided by hospitals, medical practitioners and dentists working within a hospital setting.
- **Universality:** must entitle all insured persons to health insurance coverage on uniform terms and conditions.
- **Accessibility:** must provide all insured persons reasonable access to medically necessary hospital and physician services without financial or other barriers.
- **Portability:** must cover all insured persons when they move to another province or territory within Canada and when they travel abroad.

Note: The provinces and territories have some limits on coverage for services provided outside Canada, and may require prior approval for non-emergency services delivered outside their jurisdiction.

In addition to providing funds to support health care delivery in the provinces and territories, and direct delivery of care to certain groups, the federal government also provides:

- Public health programs to **prevent disease** and educate the public
- **Health protection** that includes food safety and nutrition, and regulation of pharmaceuticals, medical devices, consumer products and pest management products
- Funding for **health research** and health information activities
- Federal health-related **tax measures** that include tax credits for medical expenses, disability, caregivers and infirm dependents, tax rebates to public institutions for health services, and deductions for private health insurance premiums for the self-employed

For more information about the role of the federal government in health care, visit the Health Canada website (<http://www.hc-sc.gc.ca/index-eng.php>) or the Public Health Agency of Canada website (<http://www.phac-aspc.gc.ca/index-eng.php>).

THE PROVINCIAL and TERRITORIAL GOVERNMENTS AND HEALTH CARE

Provincial and territorial health care includes care in a hospital and the services of a physician or other health professional (medicare). Provincial and territorial governments:

- Administer their health insurance plans;
- Plan, pay for and evaluate hospital care, physician care, allied health care, prescription drug care in hospitals and public health; and,
- Negotiate fee schedules for health professionals.

For more information about the role of the provincial and territorial governments in health care go the Health Canada website (<http://www.hc-sc.gc.ca/index-eng.php>) or follow one of links below to learn more about the specific services in your area:

PROVINCIAL AND TERRITORIAL MINISTRIES OF HEALTH

AB	Alberta Health & Wellness	www.health.alberta.ca
BC	Ministry of Health	www.gov.bc.ca/health
MN	Manitoba Health	www.gov.mb.ca/health
NB	New Brunswick Health	www2.gnb.ca/content/gnb/en/departments/health
NL	Department of Health and Community Services	www.health.gov.nl.ca/health
NS	Department of Health & Wellness	www.novascotia.ca/DHW
NT	Department of Health and Social Services	www.hss.gov.nt.ca
NU	The Department of Health	www.gov.nu.ca/health
ON	Ministry of Health and Long-Term Care	www.health.gov.on.ca
PE	Department of Health and Wellness	www.gov.pe.ca/health
QC	Ministry of Health and Social Services	www.ramq.gouv.qc.ca
SK	Ministry of Health	www.health.gov.sk.ca
YT	The Department of Health and Social Services	www.hss.gov.yk.ca

PROVINCIAL AND TERRITORIAL REGIONAL HEALTH AUTHORITIES AND ORGANIZATIONS

AB	Alberta Health Services	www.albertahealthservices.ca
BC	British Columbia Health Authorities	www.health.gov.bc.ca/socsec/contacts.html
MN	Regional Health Authorities	www.gov.mb.ca/health/rha
NB	Regional Health Authorities	www.gnb.ca/0051/regions/index-e.asp
NL	Regional Health Authority	www.health.gov.nl.ca/health/findhealthservices/in_your_community
NS	District Health Authorities	www.novascotia.ca/dhw/about/dha.asp
NT	Health and Social Services Authorities	www.hss.gov.nt.ca
NU	The Department of Health and Social Services	www.gov.nu.ca/health
ON	Community Care Access Centres	www.ccac-ont.ca
PE	Regional Health Authority	www.gov.pe.ca/health
QC	Centre local de services communautaires	www.indexsante.ca/CLSC
SK	Regional Health Authorities	www.health.gov.sk.ca/health-region-list
YT	The Department of Health and Social Services	www.hss.gov.yk.ca

PROVINCIAL AND TERRITORIAL CALL-IN HEALTH LINES

AB	HealthLink Alberta	1-866-408-5465
BC	HealthLink BC	8-1-1
MN	Manitoba Health Links	1-888-315-9257
NB	Tele-Care	8-1-1
NL	Newfoundland and Labrador HealthLine	1-888-709-2929
NS	Nova Scotia Telecare Service	8-1-1
NT	NWT Health Line	1-800-661-0844
NU	Baffin Medical Travel Office	1-866-371-3305
ON	Telehealth Ontario	1-866-797-0000
PE	Health PEI	8-1-1
QC	Info-Santé	8-1-1
SK	Saskatchewan HealthLine	8-1-1
YT	Yukon HealthLine	8-1-1

THE DRUG APPROVAL PROCESS IN CANADA

In order for a drug to be available for sale in Canada, it must go through the drug review process. The process starts when a manufacturer of the drug submits an application known as a “New Drug Submission” to Health Canada.

The New Drug Submission contains information and data about the drug’s safety, usefulness and quality. The submission also includes the results of preclinical and clinical studies, details about the production of the drug, packaging and labeling details, and information regarding the beneficial claims and side effects.

Scientists in the Therapeutic Products Directorate (TPD) of Health Canada, and sometimes, outside experts, review the safety, effectiveness and quality of the data provided in the submission, and they evaluate the potential benefits and risks of the drug.

The TPD also reviews the information that the manufacturer intends to provide to doctors and other health care practitioners and consumers about the drug. This includes the information that will appear on the drug label and related brochures. Once the review process is complete and the TPD has concluded the benefits of the drug outweigh the risks and that the risks can be minimized, the drug is approved. With Health Canada approval, the drug is issued a Notice of Compliance (NOC), as well as a Drug Identification Number (DIN). The manufacturer is now able to sell the drug in Canada.

Once a new drug has been approved and is made available to patients, the manufacturer must report any new information about serious side effects including the drug’s failure to provide its health benefit. The manufacturer must also notify the TPD about any studies that have provided new safety information.

The TPD monitors adverse events, investigates complaints and problem reports, maintains post-approval observation, and manages recalls of the drug, should that be necessary. In addition to monitoring the drugs once they are available for use by Canadian patients, the TPD licenses most drug production sites and conducts regular inspections as a condition for licensing.

SPECIAL ACCESS PROGRAM

In some cases, physicians may be able to prescribe a drug, which is not currently available in Canada through the Special Access Program. This is done in rare cases when it is the physician’s belief that other therapies have failed or are not appropriate. The drug is only released after the TPD has determined that the need is justifiable and that a qualified physician is involved.

All provinces have a special end-of-life drug plan where drugs can be covered for the last six months of life. A doctor's approval is required, and forms may be required to fill out.

COMMON DRUG REVIEW

Once a drug has been approved for sale by Health Canada, the manufacturer must submit an application to the Common Drug Review if they wish to have their drug listed on publicly funded drug plans. All provinces and territories, with the exception of Quebec, participate in the Common Drug Review (CDR). CDR is part of the Canadian Agency for Drugs and Technologies in Health (CADTH).

The CDR is a single, national process that reviews and makes recommendations to the provinces as to whether new drugs should be covered under public drug plans. The CDR was developed to help address increasing public spending on drugs. It operates under the principle that new drugs should be added to a formulary (drugs that are covered by the public plan) only after an assessment of its cost-effectiveness. Once a recommendation is made by CADTH, the province decides whether or not to include the drug on the formulary. The provinces are not required to follow the recommendations from CADTH because each plan must also consider its own health care priorities and available resources.

For more information, visit the Common Drug Review website (<https://www.cadth.ca/about-cadth/what-we-do/products-services/cdr>).

L'INSTITUT NATIONAL D'EXCELLENCE EN SANTÉ ET EN SERVICES SOCIAUX (INESSS)

Similar to the CDR process under CADTH, INESSS's mission is to promote clinical excellence and the efficient use of resources in the health and social services sector in the province of Quebec. INESSS assesses the clinical advantages and the costs of medications and interventions used in health care. It issues recommendations concerning their adoption, use and coverage by the public plan, and develops guides to clinical practice in order to ensure their optimal use.

For more information about INESSS's mission and duties, see sections 4 and 5 of the Act respecting the Institut national d'excellence en santé et en services sociaux (http://www2.publicationsduquebec.gouv.qc.ca/dynamicSearch/telecharge.php?type=2&file=/I_13_03/I13_03_A.html), or, visit their website (<https://www.inesss.qc.ca/en/>).

CLINICAL TRIAL PHASES

Clinical trials are used to measure whether a drug is safe for humans, can prevent or treat disease, how well it works, and its usefulness for other conditions. The different types of clinical trials include disease treatment, prevention and screening, as well as quality of life.

The first level of testing is known as pre-clinical. This level of testing occurs before the substance can be tested on humans. The substance is tested in tissue cultures and a variety of small animals to see if any significant changes occur. It is at this stage that the product strength and dosages are determined. Clinical trials then take place in four phases. The clinical trial process is complex and can take many years to complete. A very simple description is as follows:

- **Phase I:** 20 to 100 healthy volunteers are used to see how they respond and tolerate different doses of the substance.
- **Phase II:** 100 to 300 patients with the disease are used to measure short-term side effects and more appropriate dosages.
- **Phase III:** 1,000 to 3,000 patients with the disease are used to confirm the usefulness and further test side effects. In this phase, the final dosage is set for different types of patients.
- **Phase IV:** All studies conducted after the drug has been approved for sale by Health Canada. These tests are done to ensure the most effective use of the drug and to further support its usefulness.

If you are interested in knowing about clinical trials that are currently underway, you can access information on the following website, CanadaTrials: Clinical Research Center Profiles and Clinical Trails Listings (www.canadatrials.com).



GENETIC DISCRIMINATION

It is an individual's right not to be discriminated against, based on their disability. However, it is important to be aware that Canadian law still allows insurers and employers to ask individuals to divulge personal genetic information and their consent to have this information verified. This unfairly puts consumers under duress because they may be denied insurance coverage or employment if they fail to share their private, personal and complicated genetic information. Once this information is shared, insurance companies can then use it to unfairly determine eligibility and premiums based on the notion that the individual may be disabled in the future. Employers may also consider this information when making hiring decisions or promoting current employees.

A few facts:

- In Canada, we cannot discriminate against race, gender or disability, but we can against DNA.
- Canada is the only G7 country that does not protect the genetic information of individuals.
- Canada's lack of genetic fairness legislation acts as a deterrent for individuals considering participation in clinical trials requiring genetic testing or genetic sequencing, out of concern they and/or their loved ones may face genetic discrimination.
- Genetic information should be used to better understand the early detection, prevention, treatment, and management of diseases to allow Canadians to live longer, healthier lives.
- Insurance companies, employers and other businesses, having access to genetic information, should not be a barrier to the benefits of using genetic information for the greater good of all Canadians.

It is very important to understand the full implications of genetic testing in order to make informed decisions. For more information, go to the Canadian Coalition for Genetic Fairness website (www.ccgf-cceg.ca).



ADVOCACY TOOLS AND TECHNIQUES

POLITICAL AND SYSTEMIC ADVOCACY

Your patient organization works with federal, provincial and municipal governments, community organizations and individuals to raise awareness of specific disorders and needs of the community to improve the quality of life of the individuals living with disease that they serve. Your patient group needs your help to do this. They work diligently to engage volunteer advocates at the grassroots level as well as build partnerships with the communities they serve in order to achieve advocacy success.

Many patient groups have an advocacy program in place to coordinate efforts, creating a strong, clear and consistent messaging, which is important for successful advocacy campaigns. You can help raise your voice within these campaigns to help your community. Being part of a campaign will strengthen the chorus of the patient voice to ensure that it is heard. Involvement with your patient group's advocacy program also allows you to help direct the important issues to advocate for.

Before self-advocating, we encourage you to reach out to your patient organization. They may be working on the same issues behind the scene and need a patient voice to help them move forward with a personal story. Your patient organization may already be actively advocating for the same issue and will have the tools you need to support the campaign.

Your patient organization may not be aware of your issues, which is why it is important to reach out. This is a great opportunity to put it on the table of their advocacy initiatives. If they have limited resources, they may be focusing on one ask at a time. Helping in another area will not only benefit your community, but allow your patient organization group to then focus support to your ask. Working together makes us stronger.

If your patient organization is unable to assist you, we have a few helpful tips below on how to advocate for yourself. Please keep your patient organization updated in case they are able to offer any assistance along the way.

PERSONAL ADVOCACY

There are different kinds of advocacy –personal and issue based. Personal advocacy is when you speak about an issue that has impacted you, a family member, a friend or a loved one.

Issue-based advocacy is when you speak about an issue on behalf of a large group of affected people. This way, you not only help yourself, but also help others who may not be able to help themselves. When you speak up for yourself or an affected group as a patient, we call that patient advocacy.

Please note that sometimes you may not be speaking up to make a change, but to prevent a change that may have a negative effect on you and others. This type of action is also included in advocacy.

Advocacy can lead to meaningful change. People in a position of authority, who have the power to make changes (politicians, government officials, hospital administrators, etc.), respond to individuals and groups who are able to clearly communicate their concern and propose an effective solution.

- Identify and explain your issue
- Fit your issue within an existing government agenda or use it to set a new agenda
- Build on existing relationships with decision makers or create new relationships.

In order to establish your credibility, you need to demonstrate an understanding of the issue, as well as the facts that support your concern and proposed solution. There are three basic steps to creating an effective advocacy plan:

1. Develop your key messages
2. Create your advocacy tools
3. Focus on one main request – your one “ask”

STEP 1 – DEVELOP YOUR KEY MESSAGES

Politicians and decision makers hear different messages from many people and groups. If you want to catch their attention, make sure your message stands out and that you deliver it to the right person at the right time.

1. What - Identify your issue

- Focus on the things you are concerned about and want to see changed.
- Take a position or stand.
- If you are working with a group, make sure everyone agrees with the issues and the positions taken.

2. Why - Explain the issue

- Write out three key messages that explain your issue and your concerns in clear language.
- Your key messages must be brief, easy to remember, simple, true and provable.
- Practice presenting your key messages to family and friends who may not be aware of your issue to see if they are able to understand your concern.
- Rehearse your key messages, as they will form the basis for all written and verbal communication with decision-makers, other advocates and the media.

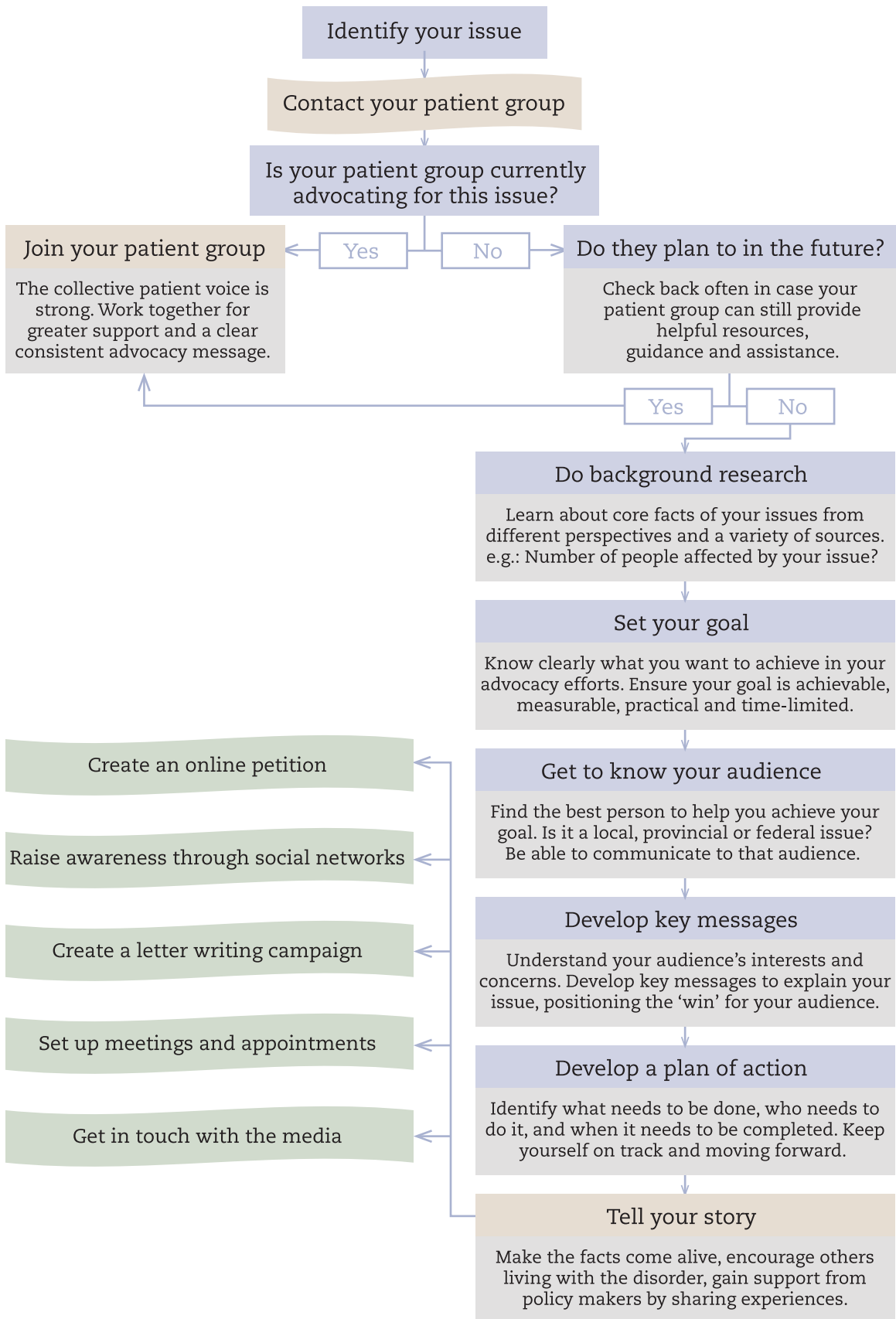
3. Who - Deliver your message to the right people

- Your issue will determine what level of government has the authority to make a change. It will be the federal, provincial/territorial, or local government.
- Once you have identified the level of government responsible, contact your local representative - either your federal Member of Parliament (MP), or your provincial representatives - Member of Provincial Parliament (MPP)/Member of the Legislative Assembly (MLA)/Member of the National Assembly (MNA)/Member of the House of Assembly (MHA), or your municipal councillor.
- Your provincial or territorial government deals with most health care issues. You can find your provincial representative by searching on the homepage of your provincial or territorial government website or the blue pages of your telephone directory.
- In addition to elected representatives, you may also contact government officials who work on health policy matters.
- Develop a plan to contact the appropriate individuals regarding your issue of concern and your three key messages.

4. When – Deliver your message at the right time

- A prime time to deliver your key messages is when the issue appears in the media and public awareness is high and in your favour.
- Another important opportunity is when a newly elected politician takes office; he or she may be looking for a new issue to support.
- An election is also a good time to share your concerns. Make sure you approach all of your local candidates with your issues to see where they stand.

Self-Advocacy Guide



STEP 2 – ADVOCACY TOOLS

There are a number of tools that can be used to deliver your message to decision-makers. Some include: in-person meetings, telephone calls, letters/faxes/e-mails, newsletters, brochures, postcard campaigns, petitions, websites, information sessions, an Advocacy Day, fact sheets, social media, etc.

Advocacy is a process. Often times, it will take a while until any sort of substantive policy change is brought into effect.

There are three components that must be followed regardless of the communication tool(s) being used:

Educate: use your key messages, your personal story and other key facts to educate the people that can make the changes you request.

Demonstrate: show how your issue matters not only to you, the group you represent, but also to the person you are trying to influence.

Advocate: once you have educated and demonstrated, it is time to make your request. Ask for the change you are seeking.

A DESCRIPTION OF SOME ADVOCACY TOOLS

Letter to your elected representative asking for a meeting

Sample outline of a letter:

- **First paragraph:** who you are (always note that you are a constituent) and why you are writing to your elected representative (your ‘ask’)
- **Second paragraph:** a brief paragraph outlining your personal story and your link to the issue
- **Third paragraph:** a combination of your three key messages and some key facts about the issue
- **Fourth paragraph:** restatement of your ‘ask’ (in bold)
- **Fifth paragraph:** *I will be in touch shortly to arrange a time to meet –*

In-Person meeting script:

- Introduce yourself and the people you are with
- Explain why you are there and your one ‘ask’
- Deliver your three key messages
- Tell your personal story as it relates to the issue
- Review some of your key facts
- Deliver your one ‘ask’ again
- Engage in dialogue to ensure your elected representative fulfills your one ‘ask’
- Conclude by saying thank you and commit to following up shortly

Fact Sheet:

- No longer than one page
- To be used as background information about the issue
- It is not necessary to deliver every key fact in your meeting
- In some cases, the Fact Sheet could be used as a leave-behind
- List province-specific information if available, as opposed to just national facts/figures
- You can find an example of a fact sheet at http://www.chpca.net/media/7622/fact_sheet_hpc_in_canada_may_2012_final.pdf

Letter to the Minister of Health:

Some issues are significant enough to write directly to the Minister in addition to your elected representative.

- **First paragraph:** who you are (always note that you are a constituent) and why you are writing to your elected representative (your ‘ask’)
- **Second paragraph:** a brief paragraph outlining your personal story and your link to the issue
- **Third paragraph:** a combination of your three key messages and some key facts about the issue
- **Fourth paragraph:** restatement of your ‘ask’ (in bold)
- **Fifth paragraph:** *I will be in touch shortly to arrange a time to meet – thank-you*

STEP 3 - YOUR ONE “ASK”

When it comes to making your request to a decision-maker, keep your request or “ask” to just one. This will urge you to focus on the thing that you need the most and not a list of things that you would like to have. If you are working on behalf of a group, selecting one ask will strengthen the consensus and support from the individual members of the group.



RECOGNITION OF SPONSORS

Innovative Medicines Canada (Canada’s Research-Based Pharmaceutical Companies) provided funding to the Health Charities Coalition of Canada during the development of this resource. A portion of that funding was used to assist us with this project. Utilization of the funds was consistent with the seven principles outlined in Innovative Medicines Canada’s *Transparency Guidelines*, which, among others, state that “*the independence and integrity of stakeholders, in terms of their operations, policies and activities, should be assured.*”

The Health Charities Coalition of Canada (HCCC) provided the majority of the funds required to develop this resource.

The members of HCCC would like to thank Innovative Medicines Canada for its support.

RECOGNITION OF CONTRIBUTORS

HCCC acknowledges with thanks, the following who contributed to the revision of the “How To” Health Guide:

The Canadian Breast Cancer Foundation for their contributions on “How to review and evaluate health information on the internet” section

Sharon Baxter

Executive Director, Canadian Hospice Palliative Care Association

Connie Côté

Executive Director, Health Charities Coalition of Canada

James Meikle

Intern, Public Policy & Stakeholder Relations, Crohn’s & Colitis Canada

Tamir Virani

Communications Manager, Canadian Hospice Palliative Care Association

2015 MEMBERS OF HOW-TO-HEALTH GUIDE WORKING GROUP

Beth Easton

Senior Advisory, Policy and Partnerships
Canadian Breast Cancer Foundation – Ontario Region

Vanessa Foran

Vice-President, Public Affairs and National Programs
Parkinson Canada

Natasha Mistry

Manager, Public Policy and Stakeholder Relations
Crohn's & Colitis Canada

2015 MEMBERS OF HCCC'S STANDING COMMITTEE ON HEALTH POLICY AND ADVOCACY

Beth Easton

Senior Advisory, Policy and Partnerships
Canadian Breast Cancer Foundation – Ontario Region

Vanessa Foran

Vice-President, Public Affairs and National Programs
Parkinson Canada

Amy Henderson

Manager, Public Policy and Health Communications
Canadian Lung Association

Lesley James

Senior Health Policy Analyst
Heart and Stroke Foundation

Gabriel Miller

Director of Public Issues
Canadian Cancer Society

Natasha Mistry

Manager, Public Policy and Stakeholder Relations
Crohn's & Colitis Canada

Seema Nagpal

Director of Public Policy
Canadian Diabetes Association

Naa Kwarley Quartey

Senior Policy Analyst
Prostate Cancer Canada

Mary Sunderland

Director of Research and Education
The Foundation Fighting Blindness

LIST OF HCCC MEMBERS

ALS Society of Canada

Information: 1-800-267-4257 or <http://www.als.ca>

Alzheimer Society Canada

Information: 1-800-616-8816 or <http://www.alzheimer.ca>

The Arthritis Society

Information: 1-416-979-7228 or <http://www.arthritis.ca>

The Asthma Society of Canada

Information: 1-866-787-4050 or <http://www.asthma.ca>

Canadian Breast Cancer Foundation

Information: 1-800-387-9816 or <http://www.cbcf.org>

Canadian Cancer Society

Information: 1-888-939-3333 or <http://www.cancer.ca>

Canadian Diabetes Association

Information: 1-800-226-8464 or <http://www.diabetes.ca>

Canadian Hospice Palliative Care Association

Information: 1-800-668-2785 or <http://www.chpca.net>

Canadian Liver Foundation

Information: 1-800-563-5483 or <http://www.liver.ca>

Canadian Lung Association

Information: 1-888-566-LUNG or <http://www.lung.ca>

Canadian Orthopaedic Foundation

Information: 1-800-461-3639 or <http://whenithurtstomove.org>

Crohn's and Colitis Canada

Information: 1-800-387-1479 or <http://www.crohnsandcolitis.ca>

Cystic Fibrosis Canada

Information: 1-800-378-2233 or <http://www.cysticfibrosis.ca>

The Foundation Fighting Blindness

Information: 1-800-461-3331 or <http://www.ffb.ca>

Heart and Stroke Foundation of Canada

Information: 1-888-473-4636 or <http://www.heartandstroke.ca>

Hope Air

Information: 1-877-346-HOPE (4673) or <http://hopeair.org>

Huntington Society of Canada

Information: 1-800-998-7398 or <http://www.huntingtonsociety.ca>

Hypertension Canada

Information: 1-905-943-9400 or <http://www.hypertension.ca>

Kidney Cancer Canada

Information: 1-866-598-7166 or <http://www.kidneycancerCanada.ca>

The Kidney Foundation of Canada

Information: 1-800-361-7494 or <http://www.kidney.ca>

Multiple Sclerosis Society of Canada

Information: 1-800-268-7582 or <http://www.mssociety.ca>

Muscular Dystrophy Canada

Information: 1-866-687-2538 or <http://www.muscle.ca>

Osteoporosis Canada

Information: 1-800-463-6842 or <http://www.osteoporosis.ca>

Ovarian Cancer Canada

Information: 1-877-413-7970 or <http://www.ovarianCanada.org>

Parkinson Canada

Information : 1-800-565-3000 or <http://www.parkinson.ca>

Prostate Cancer Canada

Information: 1-888-255-0333 or <http://www.prostatecancer.ca>

LIST OF HCCC AFFILIATE MEMBERS

The Canadian Continence Foundation

Information: 1-705-750-4600 or <http://www.canadiancontinence.ca>

The Canadian Foundation for Animal Assisted Support Services

Information: 1-888-473-7027 or <http://www.cf4aass.org>

Patients Canada

Information: 1-416-900-2975 or <http://www.patientscanada.ca>

The Sickle Cell Disease Association of Canada

Information: www.sicklecelldisease.ca



